

Testimony of Vignesh Subramanian
DS-AMBASSADOR & Patient Advocate - National Down Syndrome Society
to the CGA Public Health Committee regarding
Senate Bill 330 - *An Act Prohibiting Discrimination Against Persons with a Disability Who Are Candidates to Receive an Anatomical Gift*

Dear Chairwoman Abrams, Chairman Steinberg, and members of the Public Health Committee,

Thank you for the opportunity to submit testimony in support of [Senate Bill 330](#), *An Act Prohibiting Discrimination Against Persons with a Disability Who Are Candidates to Receive an Anatomical Gift*. I'm Vignesh Subramanian, an undergraduate student and DS-AMBASSADOR representing the National Down Syndrome Society (NDSS) in Connecticut who is spearheading the organization's effort to guarantee medically appropriate access to life-saving transplants and associated care for persons with disabilities in our state. As a patient advocate who worked directly with Senator Haskell to introduce this legislation, I am personally grateful to see this bill under consideration in this session. This bill is a critical step towards ensuring equal and fair treatment in healthcare for all under the law.

Today, thirty U.S. states explicitly prohibit discrimination by health care providers against people with disabilities seeking organ transplants. Unfortunately, many providers wrongly assume that persons with disabilities - particularly those with intellectual and developmental disabilities (ID/DD) - cannot independently manage post-operative care or else have a lower quality of life than persons without disabilities and consequently would not benefit from receiving transplants. Nondiscrimination laws prevent these physicians, hospitals, and transplant centers from denying a qualified patient access to a life-saving transplant solely on the arbitrary basis of a disability not deemed to medically contraindicate the procedure. In doing so, these laws uphold and strengthen federal protections established by the Americans with Disabilities Act of 1990, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Affordable Care Act, which prohibit disability discrimination in the rationing of organ transplants but not necessarily in patient eligibility determinations.

Shockingly, and in strong contrast to other stances this Legislature has taken on disability rights, Connecticut is not among the ranks of states with such nondiscrimination laws on the books. In the absence of a federal law prohibiting all forms of disability discrimination throughout and proceeding the transplantation process, it is imperative that our lawmakers pass this crucial legislation with all possible haste. To maximize its effectiveness, the NDSS would advise amending the bill as it stands to more closely model the framework shared with Senator Haskell and committee leadership by our organization's representatives. The amendment, if incorporated, would explicitly prohibit other forms of discrimination against persons with disabilities in the transplantation process (e.g. rejection or deprioritization of such persons on organ transplant

waiting lists, refusal to provide referrals or medical and other services related to transplantation, or declination of insurance coverage for any procedure related to receipt of a transplant or related services) and would compel providers to modify protocols, provide auxiliary aids and services, and consider all post-operative supports available to a patient as necessary to make transplantation and related services as feasible as possible.

SB 330 would ultimately codify the right of persons with disabilities to seek organ transplants, with the reasonable expectation of receiving adequate support from health care providers and without fear of being discriminated against and denied care in the process. We urge the committee to advance this bill and better secure the human rights of persons with disabilities, ensuring that they are treated as who they are: people.

Thank you for your leadership.

Sincerely,

Vignesh Subramanian

Connecticut NDSS DS-AMBASSADOR & Patient Advocate